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Community stigma and desired social distance towards people affected by leprosy in Chandauli District, India

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Summary

Objective: To collect baseline data on community stigma against leprosy and leprosy-related knowledge and ideas, with a view to develop contextualised community education and stigma reduction interventions. The data will also be used to evaluate subsequent stigma-reducing interventions.

Methods: Community members ($n = 371$) in Chandauli District, India, were interviewed, using a knowledge questionnaire, the EMIC Community Stigma Scale (EMIC-CSS) and Social Distance Scale (SDS). In the latter two scales, a higher sum score indicates a higher level of stigmatizing and negative attitudes of community members towards leprosy-affected people. Linear and quantile regression analyses were applied to explore the relation between (sociodemographic) covariates and the level of negative attitudes.

Results: Community members indicated that avoidance of people affected by leprosy, problems with (prospective) marital life, concealment, and shame and embarrassment are present. Linear regression showed that knowing people affected by leprosy and being a government employee significantly increased one's mean EMIC-CSS score, whereas a higher level of education significantly decreased this. Additionally, community members reported a desire to create social distance between people affected by leprosy and their children. Quantile regression showed that

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increased leprosy-specific knowledge and religion were associated with significantly decreased SDS scores, whilst housewives had significantly increased SDS scores. Knowledge was poorest regarding the transmission and cause of leprosy: only 8·1% and 10·5% knew the correct route of transmission and cause of leprosy.

Conclusion: The level of negative attitudes of the community towards leprosy is high in Chandauli District, which may affect many aspects of the lives of people affected by leprosy. Community members knew least about the transmission and cause of leprosy and these domains should, therefore, be considered when designing stigma-decreasing interventions.

Keywords: community stigma, social distance, knowledge, attitudes, Leprosy

Introduction

Leprosy is a chronic, infectious disease, which if left untreated may result in severe physical disability.[1] At the start of 2018 a global annual incidence of 210,617 leprosy cases was estimated, which constitutes a twofold reduction compared to the early 1990s.[2] However, leprosy remains endemic in many countries and regions, including India.[3]

The global decrease in new leprosy cases is predominantly due to two reasons, namely the introduction of effective multidrug therapies and concomitant shortened treatment duration, and the implementation of active case-finding strategies, such as contact screening and large-scale case detection campaigns. Despite these interventions, the global incidence of leprosy has remained stable for the last decade.[3–5] Therefore, leprosy elimination strategies should be intensified and improved in order to achieve this goal, but elimination strategies are hampered by leprosy-related stigma.[6–10]

Leprosy-related stigma impacts the lives of people affected by leprosy deeply, and causes delays in detection, diagnosis and treatment of the disease.[11] For example, stigma makes patients reluctant to disclose their status, thus directly affecting the effectiveness of interventions such as contact screening and post-exposure prophylaxis. Known determinants of leprosy-related stigma are a lack of leprosy-related knowledge, fear of social exclusion and contagion, and religious and cultural beliefs.[12–14] Community education about leprosy may facilitate early case-finding, and change attitudes and beliefs towards leprosy and people affected by leprosy.[6,15] Thereby, it could contribute to a reduction in leprosy-related stigma.[6,15,16] However, community education should be culturally appropriate and align with existing perceptions of target audiences to be effective.[17–21]

This study is part of the international PEP++ (post-exposure prophylaxis) Project. PEP++ refers to an enhanced PEP regimen as described by Mieras *et al.*, offered to close contacts of people affected by leprosy to prevent development of leprosy in these contacts and consequently stop transmission of disease.[22] In addition, the PEP++ Project aims to reduce the incidence of leprosy in the study area through optimized case-finding strategies, including context-sensitive community education and stigma reduction. In consultation with the National Leprosy Eradication Plan's Deputy-Director General Chandauli District was identified as a district in need of efforts to reduce the incidence of leprosy. The district reports a high rate of 17·6 new cases per 100,000 population, which is high compared to its neighbouring districts.[3,23] Additionally, to our knowledge, no research has yet been conducted into community members' perceptions regarding leprosy and people affected by leprosy in this district. This is problematic. Therefore, the main aim of this

study is to collect baseline data on community stigma against leprosy with a view to inform contextualised community education and stigma reduction interventions in the high-endemic Chandauli District. It is also explored whether leprosy-related knowledge and sociodemographic characteristics are associated with leprosy-related community stigma and desired social distance. The data will also be used to evaluate subsequent stigma-reducing interventions.

Methods

STUDY POPULATION, SAMPLE SIZE, SAMPLING AND SELECTION CRITERIA

Permanent residents of Chandauli District, aged 18 years or older, and not known to have leprosy were eligible to participate in the study. The sample size was calculated using Epi Info™ 7 StatCalc, based on an estimate of the prevalence of community members holding negative attitudes towards leprosy of 80%.[24,25] With a confidence level of 95% a minimum of 246 participants were necessary to obtain confidence limits of 5%. Stratified sampling of the target population was conducted. First, six blocks (*tehsils*) in Chandauli District were randomly selected. From each block, three to six village councils (*panchayats*) and concomitant villages were randomly selected. Thereafter, respondents were selected by convenience sampling, via a door-to-door method. Houses were selected based on whether residents were at home. However, a sampling grid based on sex and age was applied, aiming to obtain an adequate representation of the population.

DATA COLLECTION TOOLS

Before use, the data collecting tools, being the Explanatory Model Interview Catalogue-Community Stigma Scale (EMIC-CSS), the leprosy-adjusted Social Distance Scale (SDS) and a leprosy-specific knowledge questionnaire, were translated into Hindi, back translated into English and then piloted amongst 10 community members similar to the study population. Feedback, predominantly consisting of difficulties with jargon and the concept of gender instead of sex, from the pilot processes was used to optimize the data collection tools. All data were obtained via an interview-based approach. This study adhered to the definition of leprosy-related stigma as described by Peters *et al*.[26]

The EMIC-CSS, originally developed as an interview guide by Weiss in 1997, measured how community members viewed stigmatizing attitudes amongst their peers towards people affected by leprosy via 15 closed questions covering different aspects of leprosy-related stigma (*Supplement 1*).[27] Respondents had four different answer options linked to a respective score: "Yes (2)," "Possibly (1)," "No (0)" and "Don't know (0)" for each question. A maximum score of 30 could be obtained; the higher the sum score, the more negative the attitudes of the community members towards leprosy-affected people. A sum score of 8 or higher (indicative of at least four questions answered with "yes," eight questions with "possibly" or a combination of "yes" and "possibly" with a total score of 8) was maintained as the cut-off value for stigmatizing attitudes towards leprosy being prevalent in the respective community, as was done in a recent study in Thailand.[28] The EMIC-CSS is globally applied in the context of leprosy,[6,26,29–32] and has been validated in Indian regions, including West Bengal.[30]

The leprosy-adjusted SDS, originally developed by Bogardus in 1926, measures the acceptability of different levels of social distance to an affected person (*Supplement 2*).[33] Thus, the personal attitudes towards leprosy-affected persons of the interviewee and fear of leprosy are measured by assessing the social distance the respondent desires to keep towards a person affected by leprosy. Seven closed questions were asked, following the reading of a sex-specific vignette adapted to local circumstances that briefly described a cured person affected by leprosy. Each of the questions represented a different degree of social distance and four Likert-type options to answer the question were provided, each with a respective score: "Definitely willing" (0), "Probably willing" (1), "Probably not willing" (2) and "Definitely not willing" (3). A higher sum score indicated the desire to keep more social distance towards a person affected by leprosy, and thus a more negative attitude. To the authors' knowledge, the SDS has never been applied in the context of leprosy in India, but has been used in Indonesia.[26] Therefore, selected psychometric properties, including floor and ceiling effects, item interpretability and internal consistency were tested and assessed based on criteria as defined by Terwee *et al.* [34]

A sociodemographic and knowledge questionnaire comprising 15 open questions was informed by literature on relevant illness perceptions and assessed knowledge about leprosy's symptoms, cause, timeline, controllability and consequences.[35–37] A subset of five questions was selected as these specifically assessed illness perceptions. These asked about symptoms, treatment, cause, transmission in general and transmission upon treatment and were used to construct a knowledge sum score that could range from 0 to 5 (*Supplement 3*). Simultaneously, socio-demographic data, such as sex, age profession and religion were collected.

STATISTICAL ANALYSES

Data were analysed using tools provided in SPSS v. 24. Descriptive analyses of the sample population were performed. Linear regression on the mean EMIC-CSS score and quantile regression on the median SDS score was conducted to assess the association between sociodemographic characteristics and leprosy-specific knowledge, and the level of negative attitudes. To explore the crude relationship between leprosy-related knowledge and community stigma or desired social distance, Spearman's correlation coefficient was calculated. An α-level of 5% was maintained and a Variance Inflation Factor (VIF), which indicates the degree of multicollinearity, below 5 was considered acceptable. The total knowledge level was the sum of correctly answered items, including questions on symptoms, treatment, cause, transmissibility and route of transmission. An item-specific response was considered correct if one of the provided responses was correct, irrespective of whether additional answers to that question were correct or incorrect *(Supplement 3)*. Some questions only had a dichotomous response option.

ETHICAL CONSIDERATIONS

Ethical approval for the study was obtained from the Ethics Committee of Benares Hindu University, Varanasi, Uttar Pradesh (ECR/526/Inst/UP/2014). Participants were aware of their rights and gave verbal consent. No incentives were paid for participation in the study.

Figure 1. Frequency distribution of responses of community members (n = 371) to EMIC-CSS items. Percentages are provided for the respondents answering 'yes' and 'possibly'. Mean scores and concomitant 95% CIs are provided as well.

Results

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF COMMUNITY MEMBERS

Of the 371 community members included in the study, 159 were female (42·9%), 324 (87·3%) were Hindu, 141 (38·0%) had no or only primary education and all were aged between 18 and 90 years, with a mean age of 42 (SD = 17·6). A third of the respondents (30·5%) were acquainted with a person affected by leprosy.

COMMUNITY STIGMA

A total mean EMIC-CSS score of 18·0 out of 30 (95% CI 17·4–18·6) was found. Cronbach's alpha was found to be 0·75 and no floor and ceiling effects were found. Figure 1 demonstrates that over 55% of the respondents thought that leprosy-affected people would, or possibly would, conceal their disease. Also, over 85% of respondents answered that people in their community would or possibly would avoid a person affected by leprosy. Notably, a majority of respondents anticipate problems for a person affected by leprosy to get married and in an ongoing marriage (87% and 59%, respectively). In total, 94% of the respondents displayed negative attitudes towards people affected by leprosy, as assessed by the cut-off score of 8.

The relationship between sociodemographic covariates and the EMIC-CSS sum score was explored by multiple linear regression analysis. No evidence for effect modification of age and sex was found, nor were problems with multicollinearity detected. Table 1 shows that, adjusted for other covariates, a respondent's education and occupation, and knowing a person affected by leprosy, affected the EMIC-CSS score. It was found that those with primary and secondary education had reduced EMIC-CSS scores ($p = 0{\cdot}01$ and $p = 0{\cdot}05$).

Table 1. Multiple linear regression analysis: covariates in relation to EMIC-CSS sum score. ($R^2 = 8{\cdot}4\%$)

Covariate	Regression coefficient (β)	SE	*p*-value	95% CI
Intercept (β_0)	20·84			
Education				
Non-formal education (reference)				
Primary education	−2·66	1·05	**0·01**	−4·71 to −0·60
Secondary education	−1·88	0·96	0·05	−3·77 to 0·02
Higher education	−1·81	0·97	0·06	−3·73 to 0·10
Occupation				
Student (reference)				
Paid job	1·61	1·01	0·10	−0·33 to 3·65
Farmer	1·30	1·04	0·21	−0·75 to 3·36
Government employee	3·60	1·61	**0·03**	0·43 to 6·78
Housewife	1·08	1·05	0·30	−0·98 to 3·14
Other	1·78	1·34	0·20	−0·95 to 4·51
Acquaintanceship				
Yes (reference)				
No	−1·50	0·67	**0·03**	−2·82 to −0·18
Don't know	−1·36	3·33	0·68	−7·91 to 5·20
Religion				
Hinduism (reference)				
Islam	−1·53	1·04	0·14	−3·57 to 0·52
Buddhism	−2·77	2·05	0·18	−6·81 to 1·27
Leprosy-specific knowledge	−0·59	0·34	0·08	−1·25 to 0·07

In contrast, EMIC-CSS scores of government employees were 3·6 points higher than the reference category ($p = 0{\cdot}03$). An increase of 1·5 points was observed for a person knowing a person affected by leprosy, compared to those who do not knowing an affected person ($p = 0{\cdot}03$).

DESIRED SOCIAL DISTANCE

Selected psychometric properties of the SDS were measured. No floor and ceiling effects were found, for only 5·1% and 0·8% of the respondents obtained the lowest (0) or highest (21) score. No item showed multiple missing values and interviewees expressed no difficulties in understanding items upon administration of the SDS. A Cronbach's alpha of 0·84 was found.

The total mean SDS score was 6·7 out of 21 (95% CI: 6·2–7·2). Figure 2 shows a distinct pattern: respondents have a more tolerant and accepting attitude when it comes to renting out a room, being a colleague of or living next to a person cured from leprosy (68·7%, 61·7% and 67·9% definitely willing, respectively). However, when respondents were asked whether people affected by leprosy would be allowed to be a caretaker of their children, or to marry one of their children, only 31·8% and 7·0% of the respondents had an accepting attitude, respectively.

Quantile regression was applied to explore the adjusted association between sociodemographic covariates and the total SDS score, as shown in Table 2. No evidence for effect modification of age and sex was found, nor for problems with multicollinearity. It was found that housewives had significantly higher SDS scores than students ($p = 0{\cdot}01$). Muslims and Buddhists had a significantly lower SDS score than Hindus ($p = 0{\cdot}04$ and $p = 0{\cdot}01$, respectively). Lastly, it was shown that those with higher total leprosy-specific knowledge scores, had a significantly lower SDS scores ($p = 0{\cdot}002$).

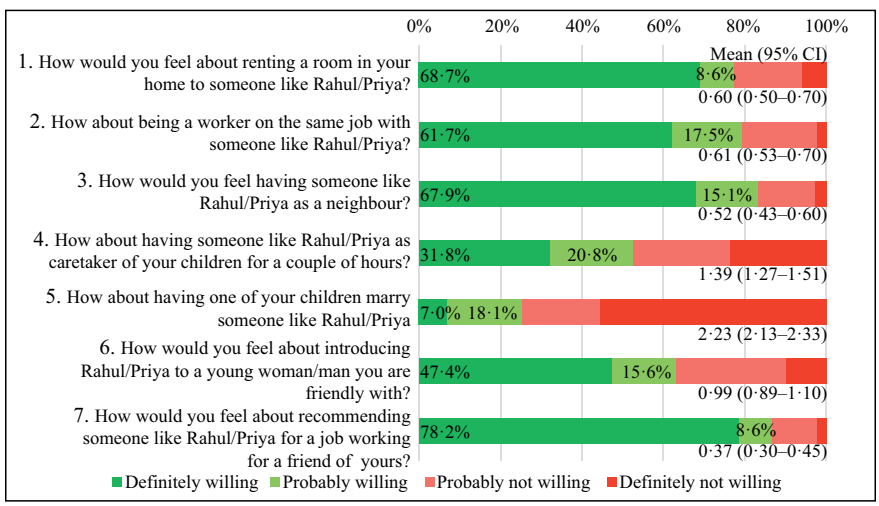

Figure 2. Frequency distribution of responses of community members (n = 371) to the SDS. Percentages are provided for the respondents answering 'definitely willing' and 'probably willing,' as well as means and 95% CIs per item.

Table 2. Multiple quantile regression analysis: covariates in relation to SDS sum score. (pseudo $R^2 = 8{\cdot}1\%$)

Covariate	Regression coefficient (β)	SE	*p*-value	95% CI
Intercept (β_0)	8·0			
Occupation				
Student (reference)				
Paid job	1·0	0·88	0·26	−0·73 to 2·73
Farmer	0·0	0·93	1·00	−1·85 to 1·84
Government employee	1·0	1·47	0·50	−1·884 to 3·88
Housewife	2·0	0·81	**0·01**	0·40 to 3·60
Other	1·0	1·21	0·41	−1·39 to 3·39
Religion				
Hinduism (reference)				
Islam	−2·0	0·97	**0·04**	−3·91 to −0·09
Buddhism	−5·0	1·91	**0·01**	−8·77 to −1·23
Leprosy-specific knowledge	−1·0	0·32	**< 0·01**	−1·62 to −0·38

LEPROSY-SPECIFIC KNOWLEDGE AND STIGMA

A correlation was observed between the EMIC-CSS and SDS scores, and the number of correctly answered questions about leprosy's cause, transmission, symptoms, treatment and contagiousness. Respectively, 25% and 42% of the participants answered one or two out of five questions correctly (Table 3). The questions answered incorrectly most frequently referred to the route of transmission and cause of leprosy: only 8·1% and 10·5% of the respondents provided the correct answer (Table 4). The crude correlation between leprosy-specific knowledge and community stigma levels was not strong, but still statistically significant (EMIC-CSS: Spearman's $\rho = -0{\cdot}113$, $p = 0{\cdot}035$; SDS: Spearman's $\rho = -0{\cdot}197$, $p < 0{\cdot}001$). This indicated that an increase in leprosy-related knowledge, measured by the number of questions answered correctly, is associated with a lower level of stigma towards people affected by leprosy within the sample population.

Discussion

The purpose of the study was to collect baseline data on community stigma against leprosy, leprosy-related knowledge and ideas to inform contextualised community education and stigma reduction interventions in Chandauli District. In addition to informing interventions, the baseline data will be used to evaluate future de-stigmatizing interventions.

EMIC-CSS: COMMUNITY STIGMA

It was found that community members perceived many stigmatizing attitudes amongst their peers (mean EMIC-CSS score of 18·0 (95% CI [17·4–18·6]). This is at the higher end of the range of scores found in similar studies applying the same scale in various Asian countries (14·4–18·0).[26,31,37,38] The domains most affected here, namely marriage, shame and embarrassment, and avoidance were found to be affected in similar studies using the EMIC-CSS as well.[6,26,38,39] Community education with a focus on these domains in Indonesia was

Table 3. Overview of the median total EMIC-CSS and SDS score per knowledge level

Number of questions answered correctly	Number of participants (%)	Median total EMIC-CSS (IQR)	Median total SDS (IQR)
0	4 (1·2%)	24·0 (21·3–26·0)	9·0 (3·0–14·3)
1	87 (25·1%)	20·0 (15·0–23·0)	7·0 (4·0–11·0)
2	145 (41·9%)	19·0 (13·0–22·0)	6·0 (3·0–10·0)
3	89 (25·7%)	18·0 (14·5–22·0)	5·0 (3·0–8·5)
4	17 (4·9%)	19·0 (16·0–22·5)	2·0 (1·0–5·5)
5	4 (1·2%)	9·5 (2·3–19·0)	1·0 (1·0–4·8)

found to reduce leprosy-related stigma substantially, as assessed by a reduction in the means of items asking about these domains and overall EMIC-CSS mean sumscore (31).

Ninety-four percent of the respondents had a sumscore of 8 or higher, indicating negative attitudes towards people affected by leprosy. This is higher than found in a previous study conducted in Thailand, in which 75·4% of the community members and 85·6% of health workers perceived negative attitudes amongst their peers.[28,38] Possibly, the high proportion of participants harbouring negative attitudes in Chandauli District is due to cultural beliefs in which leprosy is regarded as a divine punishment or as a result of karma.[40] These causal beliefs related to spirituality and religion are a global phenomenon occurring in various countries.[6,14,41] These inherently blame the patient, resulting in increased levels of stigma.[42,43]

SDS: DESIRED SOCIAL DISTANCE

The psychometric properties found in this study showed that the SDS had adequate validity to be used. We found a mean score of 6·71 out of 21 (95% CI: 6·2–7·2), which is lower than in similar studies in Indonesia and Nigeria (9·05 and 9·2, and 7·67 respectively).[26,31,39] The SDS score appears to show lower levels of community stigma than the EMIC-CSS score, which is a pattern seen in studies applying both scales.[26,31,39] A possible explanation is social desirability bias in the SDS score, since the SDS asks directly about respondents' views, whilst the EMIC-CSS asks about attitudes and practices of community members.[44]

Our findings are in concordance with the scarce literature using the same instrument to measure stigma in relation to leprosy.[26,28] The 2014 study of Peters *et al.* in Indonesia found similar domains, namely avoidance, marriage and taking care of children, to be most affected by stigma.[26] Additionally, research into stigma experienced by leprosy-affected people reveals that domains including concealment, marriage and exclusion are indeed often affected.[37,42,45] Therefore, interventions, including community education, could focus on reducing stigma in these domains.

CONCEALMENT

Almost half of the respondents report that people affected by leprosy would conceal their disease, which is in line with Nepalese and Indian studies. In Nepal 52% of the community members indicate that people affected by leprosy would conceal the diagnosis, and people affected by leprosy in India indeed conceal their disease.[37,46,47] It is argued that concealment is a coping mechanism used by people affected by leprosy to maintain their social integrity

Table 4. Overview of the proportion of participants providing correct answers to the knowledge questions

Question	Number of participants provided correct answer (%)
1. What are the early symptoms of leprosy?	193 (52·0%)
2. Do you know what causes leprosy?	39 (10·5%)
3. Do you know how leprosy is transmitted?	30 (8·1%)
4. Do you think leprosy can be treated?	329 (88·7%)
5. Do you think leprosy is contagious after the patient has been treated?	156 (45·1%)

and to prevent expected stigma, such as avoidance.[48] During the process of concealment individuals may experience a constant state of "vigilance for cues that one's stigmatized status might be expected"[49] (p. 333) followed by high levels of anxiety, distress and depression. Self-isolation may also occur as a consequence of concealment, which in itself results in impaired functioning of close relationships, as well as in facilitating the avoidance of leprosy-affected individuals by others.[11,31] Concealment also affects leprosy control efforts, as it may lead to delays in testing, diagnosis and treatment, and negatively affects adherence to treatment.[48] Therefore, concealment of disease should be mitigated as much as possible when aiming to reduce leprosy-related stigma.

MARRIAGE

Response distributions of the EMIC-CSS and SDS showed that community members indicated severe stigma-related problems in the domain of marriage. Our results are in concordance with results from studies focussing on marital relations and leprosy. Try (2006, p. 63) states that "leprosy is detrimental to marriages, both existing marriages and for the marriage prospects of unmarried individuals" and partly attributes marital problems to the fear external manifestations of leprosy cause.[50] Studies have shown that leprosy-affected individuals may be abandoned by their spouses or abstain from sexual intercourse due to fear of transmission; or prospective marriages may be cancelled.[51] Additionally, marrying a child to someone affected by leprosy might decrease the family's status, employment chances and chances of siblings getting married, which could reflect badly on the parents or the whole family.[52,53] Thus, parents may want to maintain distance between their children and leprosy-affected persons as a social protection mechanism against stigma by association. Stigma by association, or courtesy or affiliate stigma, means that negative attitudes are extended from stigmatized people to their social circle who do not have the stigmatized characteristics.[54] In addition, the perceived problems in the domain of marriage may also be attributed to the belief that leprosy is hereditary, causing a fear for a leprosy-affected descendant (publication in preparation).[55,56] Interventions aimed at mitigating leprosy-related stigma in spouses may prevent stigma in the domain of marriage.

FACTORS ASSOCIATED WITH INCREASED COMMUNITY STIGMA AND SOCIAL DISTANCE

The analyses show that occupation, education and knowing a leprosy-affected person significantly influenced the level of community stigma, as measured by the EMIC-CSS.

Leprosy-specific knowledge and religion were included in this model as well, for these covariates increased the model fit significantly. Slight differences became apparent upon analysis of the SDS scores: occupation, leprosy-related knowledge and religion significantly affected the level of desired social distance.

Differences in covariates affecting levels of stigma as assessed by the EMIC-CSS and SDS might be explained by the difference in perspective between these scales. The EMIC-CSS measures community stigma towards leprosy-affected persons, whereas the SDS measures social distance as a proxy for personal attitudes. Possibly, personal factors such as religion and leprosy-specific knowledge affect personal attitudes more strongly than the perceived attitudes of community peers. Notably, the models explained 8·4% and 8·1% of the EMIC-CSS and SDS score variability, respectively. Thus, other factors than those reported here play a significant role in the level of negative attitudes towards leprosy. These remain to be uncovered in future studies.

The association between the level of negative attitudes towards leprosy-affected persons and the level of education is in line with previous studies.[26,29,39] Evidence suggests that a higher level of education and leprosy-specific knowledge makes one more capable of resisting negative stereotypes attached to leprosy and to resist the acceptance, endorsement or enactment of stigma, which might result in lower levels of perceived community stigma.[57] Additionally, participants who knew someone with leprosy had higher levels of negative attitudes than those who did not, possibly due to having seen or experienced up-close the negative effects of having leprosy, which may increase their fear of leprosy and thus their level of stigma. The religion of respondents was also found to be significantly associated with the level of negative attitudes, as measured by the SDS. Multiple studies across a variety of contexts have shown that leprosy-related stigma, as well as stigma related to other infectious diseases, is influenced by religion.[14,50,58,59] Religious people may conceptualize leprosy as a consequence of individual or communal behaviour that violated their God-given norms or religious moral codes. This may hamper effective leprosy prevention and care.[14,60]

LEPROSY-SPECIFIC KNOWLEDGE AND STIGMA

The reported data show a weak, but statistically significant crude relationship between decreasing levels of negative attitudes and increasing leprosy-related knowledge. This suggests that improvements of only leprosy-related knowledge are unlikely to achieve large reductions in the level of negative attitudes in the community in Chandauli District. Similar results were found in studies in Nepal, India, New Zealand, Nigeria and Ethiopia.[6,37,39,61,62] The association between leprosy-related knowledge and decreases in community stigma and desired social distance is statistically nearly-significant and significant, respectively, when adjusted for additional covariates. The association between leprosy-specific knowledge and reductions in stigma must be interpreted with caution, for it is not a straightforward relation.[37] Interventions that enhance knowledge with the aim to decrease stigma should be combined with other interventions, for example with facilitated contact between community and affected persons,[20] mobilisation of change agents or champions,[63] and interventions to empower affected persons, such as counselling for affected people and their families, and socio-economic development to effectively reduce the level of leprosy-related stigma.[31]

LIMITATIONS

A limitation of this study is the non-random selection of respondents. However, we believe that our sample provides an adequate cross-section of the community in Chandauli District and is large enough to capture the prevailing perceptions regarding leprosy. Another limitation was the lack of formal validation of the Hindi version of the leprosy-adjusted SDS, which might have affected the quality of the data. This was mitigated by thorough piloting of the translated questionnaire and by calculating relevant psychometric properties, which showed that the instrument had adequate measurement validity. Also, the liberal method of calculating participants' knowledge score may have led to a small overestimation of leprosy-related knowledge. Lastly, a social desirability bias might have been present when conducting the interview-based questionnaire. This was mitigated by using two questionnaires of which one asked respondents about the community, which is less likely to be affected by social desirability.

Conclusion

Community stigma and desired social distance towards people affected by leprosy in Chandauli District were high in both absolute and relative terms, when compared to other areas and countries. Respondents believed that marital and social life (e.g. by means of avoidance and concealment) in particular were affected by leprosy and these domains should be taken into consideration when designing interventions. To reduce leprosy-related stigma and improve wellbeing of affected persons, implementation of culturally sensitive education in combination with additional interventions is required, adapted to the local knowledge. Therefore, to provide a deeper understanding of the prevalent knowledge, beliefs, norms and values regarding leprosy, in-depth qualitative research is recommended.

Disclosure of conflict of interest

The authors declare no conflict of interest. All authors declare that the answer to the questions on the competing interest form are all 'No', and therefore have nothing to declare.

Contributions

A.V. Ballering designed and planned the study, conducted data collection and analysis, and reported the study. R.M.H. Peters contributed in the design and planning of the study and reviewed the reported work. M.M. Waltz provided guidance during data analysis and reviewed the reported work. W.H. van Brakel contributed in the design and planning of the study, provided guidance during the analysis and reviewed the reported work. C.P. Mishra and M.A. Arif provided local guidance and reviewed the reported work. A.V. Ballering and W.H. van Brakel function as guarantors of this study.

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